



# Status Report

MAY 25 1994

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## Violence and disability

**U of A researcher studies links**

Lately, a more than willing media has been quick to bring the details of violent acts against people with disabilities into our living rooms. The Delvee Ranch fiasco, the Edmonton murder of Joyce Cardinal and the admission by the US. government that it performed radiation tests on mentally disabled children are all examples.

**"Approximately 15,000 children suffer long-term or permanent disability in Canada each year as a result of child abuse . . . "**

These sensationalistic accounts tend to leave some interesting questions unanswered. How widespread is violence in the lives of persons with disabilities? Why does it happen? What are the costs to society?

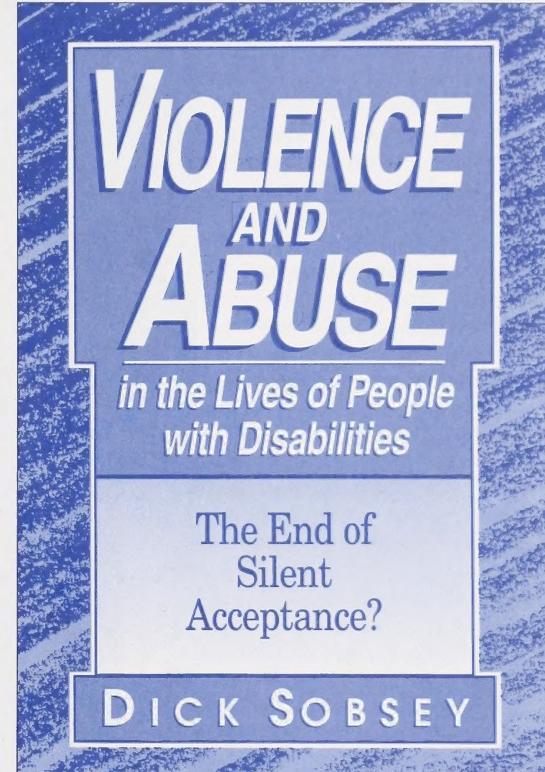
### Inside Status Report

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As one of the world's foremost authorities on the subject of violence and disability, the U of A's Dr. Dick Sobsey is addressing these questions, and the answers he's arriving at should open some eyes.

"Approximately 15,000 children suffer long-term or permanent disability in Canada each year as a result of child abuse and other forms of violence, costing taxpayers more than \$1 billion a year in health care, social services and special education costs," says Sobsey. "These costs are greatly increased when we add in children who are born with disabilities as the result of violence to their mothers during pregnancy and adults disabled as a result of violence."

Sobsey, a native of New York, first became interested in the subject some 26 years ago when he worked at an institution in that state where "violence was a major problem". Later, after his academic career was well underway, he realized that very little research was being done in the area. His research project, which has been underway at the U of A for seven years, is now recognized as being one of the top three projects of its type in the world. The fruits of his labour can be found in his recently published book *Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance?*



Sobsey's recently published book is an in-depth look at causes and prevention of violence in the lives of persons with disabilities.

Understandably, much of Sobsey's work focuses on the causes of abuse towards people with disabilities. The largest contributing factor, he says, is that society's negative response to disability allows people with disabilities to easily become victims of violence. To prove the point, he cites a recent study involving law students at the U of A who had completed their course work in criminal law. The students were given a one page description of a workplace assault by one employee against another. Half the students

(continued on page 7)

## Message from the Chairperson

# Taking the computer plunge

Gary McPherson

**I**t's an understatement to simply say that technology has benefited the lives of people with disabilities. From sophisticated electric wheelchairs to voice-activated environmental control systems, technology is giving many a new sense of independence.

But we're far from finished. In fact, at this point, I believe we're on the brink of a new revolution. The catalyst is the personal computer, which has the potential to solve even the most difficult of communication needs, whether the person be hearing impaired, deaf, blind, unable to speak, or physically disabled.

My interest in computers began in 1964, when I took part in a pilot project in programming at the U of A. My fellow classmates and I were taught FORTRAN and COBOL on an IBM 360 series, a juggernaut that completely filled an average sized classroom. My roommate stuck with programming, and he is currently employed as a systems analyst with Canadian Utilities. I, however, did not pursue it as a career. Frankly, my limited physical abilities made installation of input and output mediums (more often than not, paper) an absolute wrestling match.

Needless to say, computers have evolved considerably. For about five years now, I've been closely following their progress. Some six months ago, I realized they had reached the point where they would be a real benefit in my life. I knew they would continue to progress, but at some point you have to leap in with both feet, so to speak.

After months of research into various equipment and software types, I came to the conclusion that all had their advantages and disadvantages, and that, generally speaking, you get what you pay for. In my case, I wanted to be as independent as possible, so more expense was needed.

In the end, I purchased the Kurzweil Voice Technology package. Kurzweil is a division of Xerox. There were other excellent voice recognition packages available, but the Kurzweil package was the closest to becoming



Gary McPherson: investing in personal R & D

Windows compatible, something I see as a real advantage. I run the Kurzweil package on a NEC 486/50 with a VGA monitor. My interface is not a keyboard or a mouse, but rather, a headset microphone.

The hardware/software combination I chose hasn't been easy to master; it's required a great deal of patience. But the learning curve is exponential, and I'm now finding, after two months of use, that I'm becoming quite adept at using the system.

The technology is quite remarkable. What we're dealing with here is essentially artificial intelligence. While I won't go into detail, I will explain that the Kurzweil Voice Technology continues to learn about the way I speak, and, as it does, it adds the information into its vast library, in essence customizing itself to my particular needs in the process.

The freedom this system has given me is equally remarkable. In the past month, I've written more letters than I had in the previous fifteen years. Recently, I wrote a letter to my 83 year old grandmother, who lives in South Africa — the first letter I've written privately to her in over two decades. I can't tell you what a pleasure it is to *write* correspondence, rather than *dictate* correspondence.

What is the price for this independence? There's no denying it's steep: \$10 thousand, which I financed, and will take me three years to pay off. But frankly, I believe I'm at a point in my life where I simply can't afford not to have this technology. With the Council's existence winding down (the sunset clause has us ceasing to exist in 1998), I will soon be in a situation, like so many others, of having to market myself. While I feel I am more marketable now than at any other time of my life, many opportunities would be minimized had I not begun to acquire a certain level of computer literacy.

I have a rule I've always tried to follow: a person must invest in personal R & D. It's the only way to grow as an individual. For me, acquiring computer technology was a natural extension of this rule.

For all those considering a similar acquisition, I urge you forward with all haste. I realize the cost is inherently high, and beyond many people's reach. But I also urge you to explore other avenues of financing, from VRDP, which may be applicable if you're interested in vocational training, to grants from service clubs.

Any comments on either the technology or means of financing it? Please forward them to the editor, so that we may pass the information along to those that need it.

In closing, a quick change of topic — it is with sincere regret that I have accepted Eric Boyd's resignation as Executive Director of this Council. I will always be grateful to Eric for his leadership and seemingly superhuman efforts to increase opportunity for disabled Albertans. Since the Council's conception and before, Eric has been a true friend to me, and I will sorely miss him. My only solace is that he will continue to be a champion of persons with disabilities, this time at a federal level as he assumes the directorship of the Canadian Paraplegic Association's national office.

I wish him only the best. ♦

# Appointments

## Two new Council Members chosen

**T**wo new Council Members were recently appointed to the Premier's Council for a three year term.

Cindy Gordon has nine years experience working in the area of physical and mental disability. Currently, she is the project coordinator for the U of A-based Counselling Services for the Hard of Hearing. She is involved in numerous organizations, including the Canadian Hard of Hearing Association and the Alberta Association of Rehabilitation Practitioners. Ms. Gordon is hard of hearing.

As an occupational therapist based in Banff, Judy Eshenko works on a daily basis

with individuals with spinal cord and head injuries, multiple sclerosis, cerebral palsy and learning disabilities. In the past, she has been involved with numerous disability related projects and organizations, including National Access Awareness Week. Ms. Eshenko recently published *Free Wheelin'*, an accessibility guide to the Banff/Lake Louise area.

Both appointments are the result of vacancies created when Council Members Jim Vargo, Sandy Morrice, Wendy Bryden and Harvey Ball finished their second and final terms in the fall of 1993. ♦



New Council Members Cindy Gordon (left) and Judy Eshenko

## Thumbs up...

...to the Handicapped Housing Society of Alberta, for its work in developing Red Deer's first wheelchair accessible apartment building. Located in the city's inner core, the building features nine suites, all of which provide access to sinks, cook tops, ovens, showers, tubs, toilets, and storage space.

## Thumbs down....

...to the suggestion made by civil liberties lawyer Brian Edy that senior citizens who are denied the right to smoke in the Calgary nursing home they reside in may have grounds for an appeal to the Human Rights Commission by arguing their addiction to tobacco constitutes a disability. What's next — chocoholics applying for AISH?

# Research, anyone?

## \$1,500 grant available

**I**f you're a researcher with a disability, you might be interested in the Centennial Flame Research Award offered by the Standing Committee on Human Rights and the Status of Disabled Persons.

The award, which amounts to \$1,500 for 1994, is offered to any Canadian citizen with a disability. The recipient will use the money to fund a research project aimed at publicizing the achievements and contributions to public life of Canadians with disabilities.

Funding for the award comes from money collected from the Centennial Flame fountain in Ottawa, plus any private or corporate donations made directly to the CFRA Fund. Applications for the award will be accepted until June 3, 1994. The Committee will select the recipient according to a set of criteria, which be obtained by contacting: Clerk, Standing Committee on Human Rights and the Status of Disabled Persons, House of Commons, Ottawa K1A 0A6 Tel: (613) 992-1481, TTY: (613) 995-2266 ♦

## Status Report

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## Message from the Executive Director

# Six rewarding years

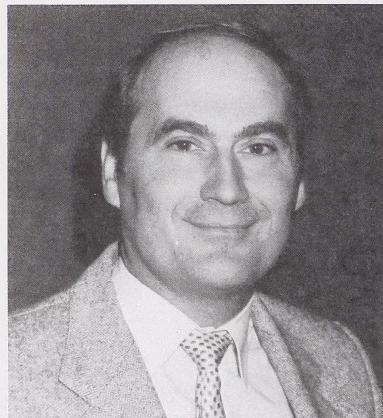
Eric Boyd

**I**t is with mixed emotions that I have tendered my resignation as Executive Director of the Premier's Council, effective June, 1994. The past six years have given me tremendous insight into how government works and the challenge of fostering change in a large organization. I have been encouraged by the shifting attitudes at all levels of government toward people with disabilities and the positive changes that have resulted.

While it's difficult to leave a body as successful as the Premier's Council, I am enthusiastic about the challenges confronting me in my new position as Managing Director of the National Office of the Canadian Paraplegic Association in Ottawa. But I realize that in order for me to assist CPA as it seeks to become even more active in disability policy at the national level, I will have to continually draw on the wealth of experience I accumulated with the Premier's Council. It truly has been six years of success.

As I reflect on the past six years at the Council, I think of the initiatives that led to the establishment of the Council in 1988. Albertans with disabilities and their representative associations felt somewhat "divided and conquered"; that their voices were not being heard. At the same time, government was being inundated by fragmented voices that seemed to lack a common direction. The resultant lack of action further frustrated people with disabilities, and the vicious circle was complete.

Ultimately, it was a growing awareness of these conflicting perceptions that brought the community together in support of a mechanism to advise government on policies affecting Albertans with disabilities (17 organizations presented the proposal to Cabinet in 1987). Government approved the proposal, believing a more united approach would help government respond to common concerns. Clearly, the greatest challenge for the Premier's Council was to present issues of the broad community of people with disabilities, while establishing and maintaining credibility with government. To my recollection, we have only lost our balance once or twice.



Eric Boyd: Ottawa bound

In the past six years, many people have asked me to describe the key reason for the Council's success in keeping disability issues high on the government agenda. My response continues to be the fact that we quickly set out to establish a strong vision in the form of the document titled *Towards a New Vision of Abilities in Alberta*. This vision document contained principles and a policy framework to guide us in our work; it was a vision that was endorsed by both community and government.

The *Action Plan* which followed provided government with a detailed strategic plan to achieve the mission of full participation for Albertans with disabilities. With the provincial government's commitment to implementation of the *Action Plan*, the community of people with disabilities and government shared not only a common vision, but also how to get there. Council's key role for the past four years has been to keep the *Action Plan* as the principle focus of policy makers' attention in the disability area. People with disabilities and their advocates deserve much of the credit for the success, because without their strong support and effective lobby this could not have happened. Let me give you some specific examples of our successes.

■ Alberta Education has supported the notion that the most effective vehicle for

the successful integration of people with disabilities is to start with children in the school system. With the recent announcement of its policy on Inclusive Education, government sends a clear message to educators that placing children in an inclusive environment will be the option of first choice. Despite major reductions in expenditures over the next 3 years, the department has minimized those reductions in programs supporting children with special needs.

- Alberta Family and Social Services has consolidated many of its support programs in a branch called Services to Persons with Disabilities, and have embarked on a three year strategic plan to provide greater equity and better coordination in the delivery of supports to people with disabilities.
- Alberta Health has demonstrated a growing commitment to increased focus on a community based philosophy and a move from the medical/institutional models. Changes in Home Care have opened up a range of supports to Albertans with disabilities under 65, while the establishment of the self-managed care option recognizes the ability and desire of many to manage their own supports. The budget in Home Care over the past 5 years has more than doubled and, despite major cuts in other areas, the program is targeted for continued expansion. A community supports model is a critical component of the department's restructuring of the health care system in Alberta.
- Alberta Transportation and Utilities has developed and implemented a flagship policy that has resulted in a coordinated approach to creating access to a broad range of public transportation options. The department, in collaboration with municipalities, the transportation industry, and consumers, has brought our province standards for pedestrian environments, accessible transit buses, inter-city buses, rapid transit, and taxis.
- Alberta Labour approved major changes to the 1991 Alberta Building Code as

recommended by the Barrier Free Design Advisory Committee and supported by the Council.

- Advanced Education and Career Development is pursuing a policy on vocational rehabilitation which, when and

## **"Six years ago, more often than not, our Council was regarded with suspicion, misunderstanding and resistance . . ."**

if implemented, will provide a much broader range of training opportunities to all people with disabilities. A pilot project currently underway in the central region whereby AFSS has transferred responsibility for providing training to

people with mental disabilities to AECD is working well, and a decision regarding total transfer of employment training to AECD is expected this fall.

- In 1990, Municipal Affairs and Housing expanded its support through the HAP program by increasing the level of the grant and improving the eligibility criteria. The department has established a cross disability advisory committee to assist in developing a provincial policy which will recognize the need for a broad range of accessible, affordable housing options for seniors and people with disabilities.
- Alberta Justice, which administers the Parking Placard program via the motor vehicle branch, announced significant changes to the program in 1993 to reduce abuse and tighten the eligibility criteria, following consultation with consumers.

Just as important as these successes, and even more gratifying for our Council, has been what I can only describe as a transformational change in the attitude of the

bureaucracy and politicians towards Albertans with disabilities. It seems that our collective efforts to promote a "culture of ability" are paying dividends. Full participation in the community is being viewed as a viable and worthwhile objective; removing the barriers being the most cost-effective way of doing it. Six years ago, more often than not, our Council was regarded with suspicion, misunderstanding and resistance by the bureaucracy as a whole. Six years later, it's viewed with respect and recognition that we provide a vital role in the coordination and development of inclusive public policy. This credibility must be preserved beyond the life of the Premier's Council.

My sincere thanks to disabled Albertans who've allowed me to speak for them, to those in government who have understood what we've been trying to achieve, and to those Council Members and members of the secretariat who have worked so hard by my side.

It's been a real pleasure, and I will miss all of you. ♦

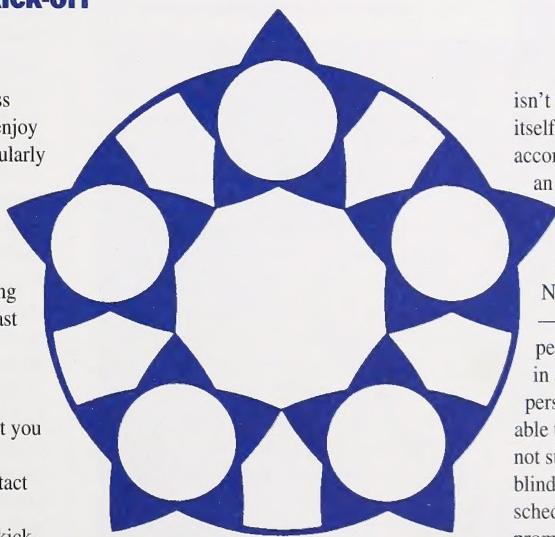
## **Prime Minister to open NAAW '94**

### **Calgary hosts national kick-off**

This year's National Access Awareness Week (NAAW) celebrations should enjoy some high profile media coverage, particularly in Alberta. Not only is the national kick-off being held in Calgary, but Jean Chretien will officially get the week underway.

The national kick-off will be a day long event, beginning with a stampede breakfast and ending with a theatre event. Other activities include a trade fair, symposium and luncheon. All events, except for the luncheon, are free, with the condition that you must register for the events you wish to participate in. For more information, contact Ruby Wingneck in Calgary at 269-3215.

Since Calgary is hosting the national kick-off, Edmonton NAAW has opted to host a wrap-up luncheon on Sunday, June 5th. Tickets will be sold in the same fashion as the breakfast tickets were sold last year. For more information, contact NAAW's provincial office at 420-0898.



"Access is Working" is the national theme for this year's NAAW. "It's an opportunity to show that we are making progress," says Norma Lorincz, NAAW's provincial coordinator. "This is not to say that there still

isn't work to be done. However, the week itself is a celebration of what has been accomplished throughout the year, as well as an opportunity to show where we still need to go."

Lorincz adds that the local theme for NAAW will be transportation. NAAW also has a new focus area this year — communication. This recognizes that persons with disabilities may face barriers in accessing information. For example, a person who is hard of hearing may not be able to enjoy a movie because a theatre will not supply assistive listening devices, or a blind person may not have access to a bus schedule. So this year, in addition to promoting awareness of physical barriers such as stairs for the wheelchair user, NAAW will promote awareness in the area of alternative communication for people who are unable to access information in traditional forms.

This year's NAAW celebrations take place May 30 to June 5. ♦

# Reaching out

## Alberta's new mental health crisis services

Cliff Bridges, Council Communications

**Q**uietly and irrevocably, the face of mental health services in Alberta is undergoing a transformation.

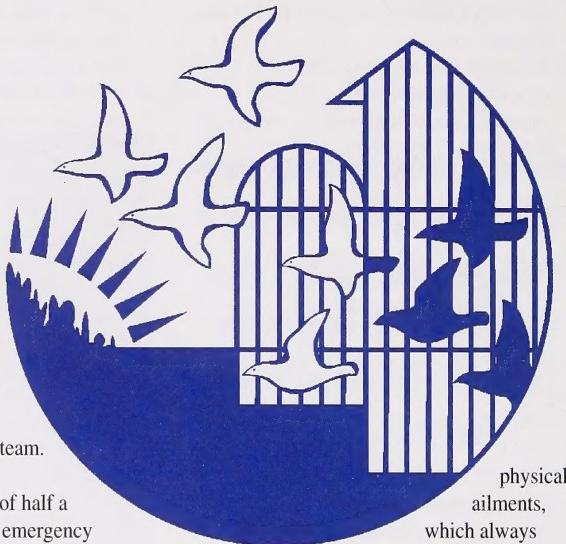
It began last August in Edmonton, with the initiation of a Mobile Mental Health Intervention Team. Anyone experiencing a psychiatric crisis between the hours of 4:00 PM and 2:00 AM can now call the Distress Line (482-HELP), where they are handled by a two member team of professionals experienced in dealing with a crisis. The team responds by giving support and guidance over the phone and, when necessary, by travelling to the person in crisis to provide the appropriate care and treatment. Back-up services, overnight treatment and shelter, and hospitalization are available as needed.

Just last month, a similar service was started in Calgary, and Lethbridge has been up and running since mid-February. Crisis intervention services are also planned for Medicine Hat, Red Deer, Grande Prairie and Fort McMurray. It's a little soon to evaluate the success of the existing services. But if the early track record of the Edmonton service is

any indication, the future looks bright for this personal, community-based type of mental health care. From startup to December 3, the service had responded to 300 calls and intervened with 108 clients. Of those, only 17 needed referral to a hospital — the remainder were successfully handled by the team.

"The ironic thing is, for \$150,000 per year, in a city of half a million people, we've made emergency psychiatric services better after five o'clock than before," says Tony Hudson, associate executive director of the provincial chapter of the Canadian Mental Health Association (CMHA).

The key, according to Hudson, is that the team is mobile — it travels to the person in crisis, rather than the person in crisis travelling to the nearest hospital emergency ward. "In hospitals, you're dealing with



physical ailments, which always seem to have priority, so people have sat for six, eight, even ten hours. Obviously, if you're experiencing a mental or emotional crisis, that's not where you want to be."

Besides the holistic benefits of treating people in their own communities and homes, Hudson says there are also significant savings to the health care system to be realized with the new approach. "It could save a bundle," he frankly admits.

CMHA, as well as other local community organizations, has been pushing for a service like this for some time. But Hudson is quick to point out that the Mental Health Division of Alberta Health has been one of the driving forces, from idea to operationalization.

"They've been clear for some time that they needed to fill in a continuum of care," he says. "So I would say it's a combination of a vision coming from Alberta Mental Health and the community responding and tailoring the programs to their own needs."

In this time of fiscal restraint, you may find yourself wondering who's funding these crisis intervention programs. The simplest answer is that they are a partnership; a marriage of government and community. For instance, in Edmonton, core funding comes from Alberta Mental Health. One staff member (there are two teams) is seconded from Mental Health, one from Alberta Hospital. The service itself is housed in The Support Network, an Edmonton society that responds to personal and community needs.



CMHA's Hudson: "The ironic thing is . . . we've made emergency psychiatric services better after five o'clock than before."

The Edmonton Police Service provides security, while Edmonton's acute care hospitals guarantee hospital beds, if needed, on a rotating basis. Members of the advisory committee come from all sectors — government, the medical community, Edmonton Police Service, CMHA, and a multitude of community organizations. According to Hudson, services in other areas will use this same partnership approach, although some of the members may differ.

With its emphasis on community instead of institution, mobile crisis intervention truly represents a paradigm shift. Yet, when you talk to people who have been instrumental in bringing about this change, it's obvious they think this is the tip of the iceberg.

"I can see this program as a stepping stone to something even greater," said Denis Ostercamp, director of service delivery for Mental Health Services, during a recent press conference announcing the Calgary service.

**"Everybody involved in mental health has to look at what they're doing Monday to Friday, 8:30 to 4:30, because those hours may be obsolete."**

Hudson is even more enthusiastic. "It has the potential to be a linch pin kind of service, where it can really fuel the creation of a whole new way of doing things. Crisis services could do everything, from meeting the person in the crisis, to getting them shelter, linking them with regular services, and operating as a gatekeeper to the hospital system.

"Everybody involved in mental health has to look at what they're doing Monday to Friday, 8:30 to 4:30, because those hours may be obsolete."

For more information on the crisis intervention service in your area, call your local office of the Canadian Mental Health Association or the Mental Health Division of Alberta Health at 427-2816 (toll-free through RITE directory). ♦

## Eyes-on computing Video camera replaces keyboard

A Fairfax, Virginia company has developed a method of controlling a personal computer with the eyes.

The Eyegaze System, developed by LC Technologies Inc., enables people with severe motor disabilities to do many things with their eyes that they would otherwise do with their hands. Simply by looking at control keys displayed on a computer screen, the user can perform a broad variety of functions including speech synthesis, environmental control, operation of DOS-based software, playing games, typing and operating a telephone.

The system operates by judging where the eyes are focused on the screen. A video camera located below the screen continually

observes the eye, and specialized image-processing software determines the eye's orientation and projects the gazepoint on the computer display. With a person sitting 18 to 22 inches from the screen, the system is accurate to within a quarter inch, enabling the user to control entire on-screen computer keyboards. Nothing is attached to the head or body.

Eyegaze Systems are currently being used by people with a wide variety of disabilities, including spinal cord injuries, cerebral palsy, and ALS.

For more information contact LC Technologies, 9455 Silver King Court, Fairfax, VA, USA 22031, (703) 385-7133. ♦

## Violence and disability (continued from page 1)

were told that the victim was mentally disabled, half were not. In the half that were told the victim was disabled, eight times as many thought a suspended sentence was appropriate.

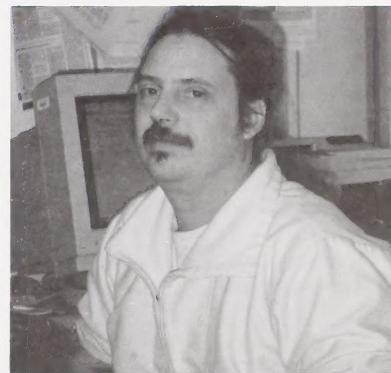
"That kind of information," says Sobsey, "suggests that some of the attitudes that disinhibit violence in the offenders are not just attitudes that a few offenders have, but are attitudes that exist throughout our society."

By far the most important issue needing resolution is how to prevent violence and abuse from taking place. "Isolation and lack of attachment are big risk factors," says Sobsey.

Therefore, he adds, people with disabilities need true community integration and extensive personal networks. "We've got good evidence now that children growing up in an institution are twice as likely to be abused as children growing up in a regular family."

Sobsey also cites the need for people working in the area to share their knowledge, and, to that end, he has organized a national roundtable discussion on violence and disability, scheduled for May 17 in Edmonton. The roundtable will be attended by a wide range of people, including people with disabilities, researchers, judges, police, etc.

"The plan is to use that as a consultation,



Dr. Sobsey

and from that to bring forward an agenda document that will discuss what various programs can do, and what direction research should take." ♦

The national roundtable on violence and disability will coincide with the SHAPE '94 conference (SHAPE — Severe Handicaps Alliance for Public Education), to be held at the Fantasyland Hotel and Convention Centre in Edmonton from May 18 to 21, 1994. For more information on the conference, roundtable or Dr. Sobsey's violence and disability project, please contact Gill Rutherford at 492-1142.

# Disability rates soar for aboriginals

## Links made to poor living conditions

A recently released report from Statistics Canada reveals that incidence of disability for aboriginals is roughly twice that of other Canadians.

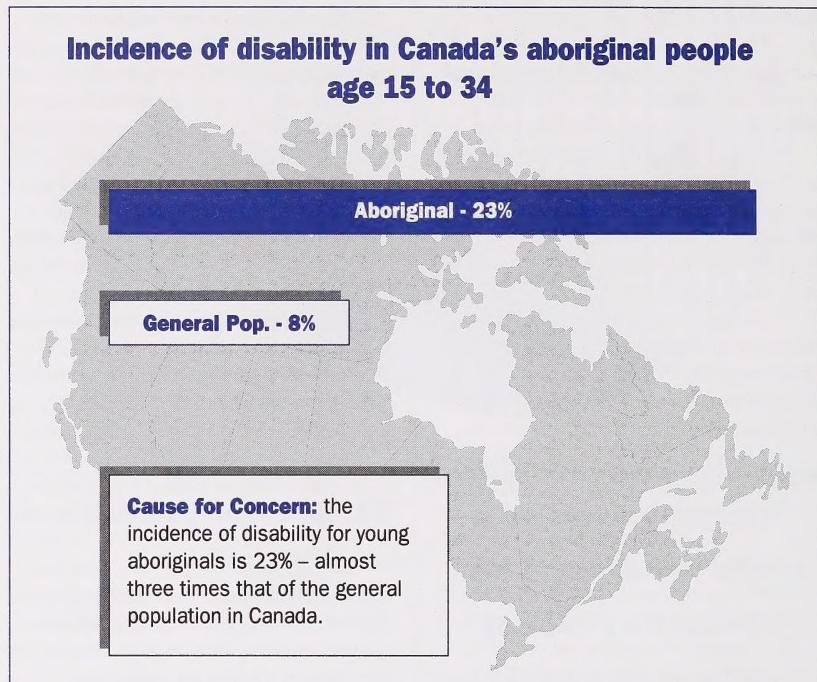
The special aboriginal survey, which was part of the 1991 census, showed that 31 per cent of Indian, Metis and Inuit adults reported some form of disability, compared with 15 per cent of the total population.

There are several other disturbing statistics from the survey:

- one in four young aboriginals (age 15 - 34) reported disabilities — three times the national average.
- 35 per cent of disabled aboriginals had hearing problems, compared with about 23 per cent of general disabled population.
- About 24 per cent of disabled aboriginals reported problems with sight, compared with about nine percent of the general disabled population.

The StatsCan survey indicates that the high rate of disability incidence among aboriginals can be directly linked to substandard living conditions in aboriginal communities and reserves. The results show that the dwellings of aboriginals are twice as crowded with fewer amenities than the average Canadian household.

The Premier's Council has addressed the issue of high disability incidence among



aboriginals in Alberta. In the fall of 1993, the Council released a report entitled *Removing Barriers: An Action Plan for Aboriginal People with Disabilities*. This in-depth report outlines the difficulties experienced by disabled aboriginals, and makes detailed

recommendations to alleviate the problems.

An interdepartmental committee chaired by Alberta Education is in the process of preparing a response to *Removing Barriers*. This response is expected by June of this year. ♦

## The RITE changes

### Easier access to government telephone system

As of April 1, 1994, the Alberta government is offering a new service that will allow Albertans to call government from anywhere in the province with a single, province-wide toll-free number — 310-0000.

The number eliminates the 35 numbers that previously composed the Regional Telephone Inquiries (RITE) system. Regardless of their location, users of the new system can dial the single number and their call will be routed automatically to the nearest RITE centre.

The RITE system handles about six million calls a year. Established 20 years ago, the system was designed to give all Albertans toll-free access to government, while reducing the cost of government long-distance calling. The new system is expected to result in savings of \$900,000 over the next three years, and \$1 million per year after 1996-97.

Eight small communities will not have access to the new 310-0000 service until the end of 1994, when the technology will be

available in those areas. The 800 homes served in these areas will continue to use the existing 1-800-565-7483 RITE number. These centres are Assumption, Cadomin, Chipewyan Lake, Little Buffalo Lake, Peerless Lake, Red Earth, Meander River and Zama.

TDD/TTY service will not be available using the new number. Deaf and hard of hearing Albertans will call 1-800-232-7215 (toll-free) unless they live in Edmonton, where the number to call is 427-9999. ♦

# A new approach to Alzheimer care

## Innovative housing for people with Alzheimer disease

**S**mall, home-like residences for people with disabilities are not particularly new. In fact, they are part of neighbourhood communities throughout Canada and the United States. Until recently, however, little attention has been given to people with Alzheimer disease who are unable to live at home. Their choices are currently limited to auxiliary hospitals or nursing homes.

Last January, Edmonton-based Capital Care Group announced plans to build a 36 bed residential centre for people with Alzheimer disease — the first of its kind in Canada. Located in northeast Edmonton, the building is planned to be comfortable, calm, secure and uncomplicated.

The one-story building includes three residences joined together by a common space. Each house will have its own garden, kitchen, living and dining room. Residents will be able to wander freely from one house to the other. There will also be free access to gardens, pathways and quiet places to rest.

By assuming this project, it appears the Capital Care Group is attempting to break away from the traditional model to one which offers more flexibility and is driven by the needs of the resident. The daily routine in the Centre will give foremost consideration to choices, personal autonomy and



- Photos courtesy Perkins Eastman and Partners

Edmonton's Alzheimer Care Centre will be similar to this facility in Oakmont, Pennsylvania.

independence. For example, residents, who are able, will decide when and what to eat, how to spend their days, when to go to bed and when to get up in the morning. All of this represents a shift in philosophy from the routine, procedure and dependency of a hospital model to a strong emphasis on the spiritual, social and physical dimensions of the individual.

"Formal research, coupled with the popularity of similar residences in Sweden and the United States, clearly illustrates that residents are healthier and happier in a 'non-hospital' environment," says Veronica Scott, Communications Coordinator for the Capital Care Group.

Scott adds that the decision to build the care centre was prompted by consumer demand. "Caring for a family member at home on a full-time basis can

be both physically and emotionally exhausting, especially if the individual is confused, aggressive and wanders at night. The decision to place a loved one in a continuing care centre is often difficult. Many families suffer from a great deal of anxiety and guilt when having to make this difficult decision. With the Alzheimer Care Centre, the intent is to provide people with an alternative that approximates residential housing."

Alberta Health is providing the operating funds (staffing) for the Alzheimer Care Centre, which will be located in northeast Edmonton. These funds are the result of the closure of long term care beds at the U of A Hospital. Building costs of \$2.5 million are being supplied by the Capital Care Foundation through a fund-raising campaign.

The Centre will accommodate a total of 36 residents, but research and outreach components will make it possible to assist many other people indirectly. The Centre will maintain practical research links to the U of A's Centre for Gerontology. As our population ages and the incidence of Alzheimer disease increases, understanding more about this complex disease will ultimately benefit many Canadians.

For more information about the Alzheimer Care Centre, contact the Capital Care Group at 448-2414 and ask for Karen Van Sacker. ♦



A common area joining the three houses will serve as a centre for a variety of activities for residents and visitors.

# News for disabled travellers

## NTA imposes new training regulations; a newsletter for disabled travellers

For people with disabilities, travelling poses some unique problems. What destinations are accessible? How do I get there? Where can I find more information?

The answers to these questions can be found in the pages of new publications geared specifically for disabled travellers. *We're Accessible — News for Disabled and Elderly Travellers* is a quarterly newsletter that features stories about subscribers' travels around the globe, lists of resources, readers' tips and questions answered, and a network exchange forum for those willing to pass on information about their area to fellow travellers.

The spring 1994 issue contains information on London, bed and breakfasting in BC, Hawaii, the Grand Canyon, and Costa Rica. While some of the writing and layout seems to be lacking, the newsletter is chock full of useful information. Individual subscriptions are a modest \$15 per year. For more information, contact Lynn Atkinson, Editor, 32 - 1675 Cypress Street, Vancouver, BC



V6J 3L4 Tel. (604) 731-2197.

Meanwhile, new regulations imposed by the National Transportation Agency (NTA) will help ensure that transportation employees across Canada will be suitably trained to provide services to persons with disabilities.

Under the new regulations, rail, marine and air carriers, as well as terminal operators, are required to train their employees and contractors to provide suitable transportation services to disabled travellers. Training must be completed by January 26, 1995, which is when the new regulations take effect.

The new training regulations were developed after consultations with the industry and persons with disabilities. Other regulations currently being developed by the NTA will apply to air fares for attendants, uniform standards of accessibility of equipment, and terms and conditions of transportation in other modes of transportation under federal jurisdiction.

The new regulations support the National Transportation Act (1987) and the goals of the National Strategy for the Integration of Persons with Disabilities. ♦

## The latest in disability video managing personal assistance; stuttering; etc.

This spring sees some excellent new videos available to persons with disabilities.

The first offering is actually a series of videos produced by Grant MacEwan Community College in Edmonton. *Making Your Own Way* (\$120) illustrates a step-by-step approach to identifying needs, recruiting appropriate personal assistants, and communicating effectively with them. The videos are coupled with a written guide (\$29.95) titled *Steps to Independence: A Guide for Managing Personal Assistance*. For more information, call 497-5117.

Deaf and hard of hearing Albertans might be interested in *Breaking the Sound Barrier*, recently produced by the Government of Canada's Employment Equity Branch. *Breaking the Sound Barrier* shows how deaf and hard of hearing people can access the

Canada Employment Centres. Using sign language, deaf actors tour a typical Canada Employment Centre, explaining how to obtain information on job opportunities, job search methods and how to prepare yourself to look for work. The video also includes on screen captions and narration. For more information, call 1-800-465-7735 (TDD).

Finally, two recently released videos deal with the poorly understood disability of stuttering. *Speaking of Courage* and *Voices to Remember* are documentaries that feature real people and examine the impact stuttering has on their lives. Both films were written, produced and directed by Vladimir Bondarenko, who stuttered during his youth but went on to become a teacher, actor and musician. For more information, contact Johanna Shore at 1-800-263-1818. ♦

## Opportunity for disabled artists

An upcoming art show in Edmonton will feature the work of visual artists with physical disabilities. *An Afternoon in June: A Celebration of the Arts by Persons with Disabilities* will take place at the Sidetrack Cafe on June 4th. All work shown will be offered for sale, with half the proceeds going to the artists, and half going towards the FES (Functional Electric Stimulus) Clinic at the Rick Hansen Centre at the U of A.

Artists are invited to submit up to three original works of art in various mediums, along with a personal biography and an inventory sheet describing the artwork and current market value. Submitted pieces must be framed using museum quality materials.

Deadline for submission of artwork is May 15. For more information, contact Bill Miller by leaving a message at 492-7091. ♦

# New personal health numbers

## System will streamline record-keeping

**A**lberta health will soon be giving all eligible Albertans (including children) their own personal health numbers to replace their current registration numbers. Albertans will get their new numbers when they receive their new personal health cards in May and June.

Personal health numbers have nine digits separated by a dash in the following format: 99999-9999. Albertans will keep the same personal health numbers for life.

The first time patients see a health provider, they will have to present their new personal health card. However, once providers have the new numbers on file, they shouldn't

need to see their patient's cards again.

Alberta Health cites two reasons for adopting the new system. Personal health numbers will help the department record health information more consistently, which will allow it to better monitor how well the health system is working.

As well, personal health numbers will help streamline record-keeping throughout the health system, since all health providers will use the same personal health number to record and store health information. This will be a great improvement over the existing system, where Albertans could have several different health numbers throughout their lives, with

the result being different health providers having different registration numbers for the same patients.

All eligible Albertans will receive their new cards by July 1, provided Alberta Health has a current address for them. If any Alberta residents haven't received their cards by July 15, they should contact Alberta Health:

Edmonton: 427-1432

Calgary: 297-6411

Outside Edmonton or Calgary, call toll free using the RITE network (the new RITE number is 310-0000). ♦

# Tetra arrives in Edmonton

## Society specializes in low-cost technical aids

**T**etra Development Society, which has existed in Vancouver for three years, has been rapidly expanding across Canada. Last year, a chapter was formed in Calgary (see Status Report, November 1993). Now, an Edmonton chapter is up and running.

For many people with physical disabilities, independence is often achieved with the help of technical devices that assist in everyday activities. The problem, however, is that many devices are either quite expensive, not suited to an individual's specific needs, or simply don't exist. Enter the Tetra Development Society.

Tetra's concept is beautifully simple: match volunteer technicians and engineers with persons with disabilities, with the goal of creating a low-cost device that provides greater independence or eliminates obstacles in the disabled person's environment.

The program uses a partnership approach, with a coordinator's only involvement being matching a client's needs with the most suitable volunteer.

Examples of work done by Tetra engineers are ingenious and many. They include:

- a compressor and inner tubes to lift the user — who has muscular dystrophy — to a standing position.

- an eating machine, made from such items as an electric car window raiser, a hospital bed, and a sewing machine. The user, who has ALS, is able to eat independently.
- a retractable canopy for an electric wheelchair that keeps both the user and the chair's delicate electronics dry.

Tetra's services are offered at no charge. The only costs to the client are materials and mileage for the volunteer. Often, materials are donated or recycled, so the charges are minimal.

Generally speaking, Tetra will not develop devices that are available commercially. Projects taken on are usually not considered essential for the health and safety of the consumer.

Tetra was founded by Sam Sullivan, who became a quadriplegic after a skiing accident. Determined not to rely on social assistance, which he describes as "a safety net which can all too easily discourage personal initiative and turn into a trap", Sullivan set out to regain

independence in his life. He quickly realized that technology could be a liberator.

Sullivan made contact with a group of engineers, who soon completed a number of projects for him and some of his friends. The group then formalized its efforts under the name Tetra Development Society. It was founded and is run entirely by people with severe disabilities.

The society operates with no core funding, relying instead on contributions and grants from a wide variety of sources.

For more information or to request an application form, contact one of the following Tetra representatives:

Laurie Purches  
c/o Easter Seal Ability Council  
Suite 216, 11010 - 101 Street  
Edmonton, Alberta T5H 4B9  
Tel: 429-0137

Guy Coulombe  
c/o Canadian Paraplegic Association  
Suite 305, 11010 - 101 Street  
Edmonton, Alberta T5H 4B9  
Tel: 424-6312 ♦



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## Coming events

### Seminars, symposiums, conferences, meetings

Severe Handicaps Alliance for Public Education presents Shape '94 Conference. May 18 - 21, 1994, in Edmonton. Theme: international discussion dealing with all aspects of disability, with focus on "shaping each other's lives". Contact: Gill Rutherford, 6-102 Education North, U of A, Edmonton, AB T6G 2G5 Tel: 492-1142.

Canadian Hard of Hearing Association presents National Conference 1994. May 26 to 29, 1994, in Calgary. Theme: four day conference discussing all aspects of hearing loss. Contact: CHHA Calgary, Box 521, 3545 - 32 Avenue N.E., Calgary AB T1Y 6M6.

Wild Rose Foundation presents Vitalize '94 Provincial Volunteer Conference. June 9 - 11, 1994, in Grande Prairie, Alberta. Theme: volunteers are family. Contact: John Kopeck, Special Projects Consultant, at 422-9305 (toll free through government RITE operator).

Canadian Paraplegic Association presents Aging with a Spinal Cord Injury. June 16 at the Westin Hotel in Edmonton. Theme: one day discussion dealing with the implications of aging with a spinal cord injury. Contact: CPA at 424-6312.

The University of Calgary presents Entrepreneurship and Disability. July 4 - 8, 1994 at the U of C. Theme: five day workshop focusing on the variety of entrepreneurial

initiatives by and for persons with disabilities emerging throughout Canada and the world. Contact: Rehabilitation Studies, Rm. 413 Ed T, U of C, Calgary AB T2N 1N4.

The University of Calgary presents Research, Development and Application of Computer Technology for Persons with Disabilities. July 11 - 15, 1994 at the U of C. Theme: five day workshop focusing on the use of emerging computer technology as a communication tool for people with disabilities. Contact: Rehabilitation Studies, Rm. 413 Ed T, U of C, Calgary AB T2N 1N4.

The University of Calgary presents Career Development and Disability. July 5 - 16, 1994 at the U of C. Theme: two week course intended to develop skills necessary for career advising with persons with disabilities. Contact: Rehabilitation Studies, Rm. 413 Ed T, U of C, Calgary AB T2N 1N4.

Schizophrenia Society of Canada presents 1994 Annual Conference. August 12 - 14, 1994, at the Ottawa Congress Centre. Theme: celebrating fifteen years of families helping families. Contact: Schizophrenia Society of Canada, 75 The Donway West, Suite 814, Don Mills ON M3C 2E9.

The Learning Centre presents 8th Annual Summer Institute. August 15 - 17, 1994, at the Learning Centre in Calgary. Theme:

understanding and assisting individuals with learning difficulties. Contact: The Learning Centre, 3930 20th Street SW, Calgary AB T2T 4Z9 tel. 686-9300.

Canadian Association of Independent Living Centres presents National Independent Living Conference 1994. August 24 - 27, 1994, in Winnipeg. Theme: progress through partnerships. Contact: 201 - 294 Portage Avenue, Winnipeg MB R3C 0B9 Tel: (204) 989-2317 TTY: (204) 947-0194.

Canadian Mental Health Association presents CMHA 1994 National Conference. November 2 - 5, 1994, in Calgary. Theme: innovations and alternatives in mental health. Contact: Conference Coordinator, 1994 National Conference, CMHA, #103 723 - 14 Street NW, Calgary AB T2N 2A4 Tel: 297-1700.

Is your association or agency sponsoring a provincial or national conference or workshop? If so, please forward the pertinent information to:

The Premier's Council on the Status of Persons with Disabilities  
250, 11044 - 82 Avenue  
Edmonton, Alberta T6G 0T2  
Tel: 422-1095 (Edmonton)  
or 1-800-272-8841 (rest of Alberta)  
Fax: 422-9691

## The last word

Knowledge, ability, experience, are of little avail in reaching high success if courtesy be lacking. Courtesy is the one passport that will be accepted without question in every land, in every office, in every home, in every heart in the world. For nothing commends itself so well as kindness; and courtesy is kindness.

— George D. Powers